

SUMMARY OF ADVISORY COMMITTEE MEETING  
Virginia Early Hearing Detection and Intervention Program  
Virginia Department of Health  
May 11, 2007  
DRAFT

The following persons attended the meeting of the Virginia Early Hearing Detection and Intervention (EHDI) Program Advisory Committee: Barbara Allen, Jeannine Beden, Bob Boyle, Mark Campano, Brian Campbell, Pat Dewey, Mary Ann Discenza, Darlene Donnelly, Leslie Ellwood, Ruth Frierson, Fredia Helbert, Ann Hughes, Loucendia Lambert, Stephanie Moody-Antonio, Casey Morehouse, Debbie Pfeiffer, Leslie Prince, Beth Tolley, Susan Ward, Dana Yarbrough, and Ellen Rolader, guest.

**Announcements and Updates**

- Frank Aiello sent information to update the group on the activities of the federal Department of Health and Human Services (HHS) Working Group on Closing The Gaps in Services to Infants and Young Children With Hearing Loss. Dr. Margaret Giannini, Director of the HHS Office on Disability, sent two letters to further implement the recommendations of the Working Group. The first was to key national organizations of service providers for children with hearing loss from Dr. Giannini, in which she requested that their members promptly refer all children with hearing loss to Part C in order to close the gaps in the referral phase of service provision. The second was a jointly signed follow-up letter from Assistant Secretary Hager and Dr. Margaret Giannini to Part C Coordinators, stressing the importance of addressing the essential issues of providing prompt and effective early intervention services.
- Ruth Frierson, EHDI Follow-Up Coordinator, was recognized by the Commissioner of Health as a Public Health Hero. This recognition is part of the Governor's recognition of public service and to salute excellence in the public workforce.
- Stephanie Moody-Antonio announced that the Coalition for Hearing Education and Research (CHEAR), a preschool, oral, deaf education program for children aged 1-6, has officially been incorporated. They are looking for an Executive Director and expect to begin fund raising over the next couple of months. The goal is to have the preschool open in 2008.
- Mark Campano announced that the Virginia Project for Children with Dual-Sensory Impairments had received funding from both Virginia Department of Education and EHDI federal grant funds for In-home Sensory Impaired Training and Education (INSITE) training. The INSITE program offers home-based support and resources for families with infants, toddlers and pre-schoolers, age birth to five, with sensory impairments and additional disabilities. The summer institute conference this year, Pathways to Possibilities, will be held August 8 - 10 at the Sheraton Park South in Richmond, Virginia. It will provide content for professionals and family members who work/live with students with visual impairments and/or multiple disabilities including Dual Sensory Impairments/Deaf-Blindness.
- Beth Tolley announced that a private early intervention provider group, in collaboration with JMU, is sponsoring auditory verbal therapy training. The training is scheduled in three courses lasting two days each and will be held at the Shenandoah Valley Inn in Staunton, Virginia. The dates are June 1-2, 2007, October 5-6, 2007, and February 1-2, 2008.
- Beth Tolley reported that she attended a one-day conference on Facilitating Spoken Language, sponsored by Cochlear Corporation. The information was very informative and was presented in a non-biased manner.
- Ann Hughes announced that the inaugural conference for educational professionals working with students who are deaf and hard of hearing will be called Unlocking Opportunities Unleashing Potential and will be held August 8-9, 2007, in Staunton. Attendance is limited to 100 participants. The presentations will provide opportunities to learn strategies for effective instruction and

connecting with State resources in the areas of communication, technology, literacy, and transition. The keynote speaker will be Dr. Sue Schwartz, author of Choices in Deafness: A Parents Guide to Communication Options. The objective is to train parents and professionals on how to work together to reach decisions. Also, on August 10, 2007, there will be a Visual Phonics© workshop. See-the-Sound Visual Phonics© is a system of 45 hand gestures that are suggestive of the English sounds they represent and written symbols that suggest these hand gestures. Visual Phonics© is a tool that facilitates the teaching of reading, writing, and speech. Finally, Virginia Network of Consultants (VNOC) will be presented as a service model for other states at the American Instructors of the Deaf national conference in June.

- Fredia Helbert announced that Dr. Walter Nance, member of the EHDI Advisory Committee, was a featured speaker on the genetics of hearing loss at the American Academy of Audiology national conference. Also, EHDI grant funding supported audiology speakers at the Speech-Language-Hearing Association of Virginia conference in March. Jackson Roush and Jackie Busa, parent and member of the EHDI Advisory Committee, gave two presentations.
- Debbie Pfeiffer reported that she and Ann Hughes attended the "State Leaders' Summit on Deaf Education", May 7 - 9, in Columbia, MD. Nancy Armstrong, Superintendent of Virginia School for the Deaf and the Blind at Staunton, and Irene Schmalz, consumer, parent, and Virginia Guide By Your Side (GBYS) trained guide, made up the rest of the Virginia team. This was the third year that the meeting was held; teams representing about 35 states attended. The purpose was to ensure that states are working toward meeting goals of the National Agenda (from the document, The National Agenda: Moving Forward on Achieving Educational Equality for Deaf and Hard of Hearing Students). States reported out on their progress and shared ideas for meeting objectives.
- Casey Morehouse informed the group that the parent infant outreach specialist position at the Virginia School for the Deaf and Blind in Staunton position has been cut. She asked the committee's help with any suggestions or methods to have the position returned to the budget or to find a way to fill the service gap that now exists. Also, in the latest edition of the ASHA Leader, there is an article on newborn hearing screening and addresses experiences of parents when they learn their child is deaf.

### **Report from Virginia Department of Health**

- Interviews for the Surveillance and Evaluation Coordinator have been completed and the top candidate has accepted the position. Her name is Michelle Ballard; she will begin work on May 25. She has a Master of Public Health degree.
- As reported at the last meeting, Virginia has the opportunity to work with the National Center for Hearing Assessment and Management (NCHAM) on the Early Childhood Hearing Outreach (ECHO) project. This is an NCHAM project that focuses on hearing screening and follow up for the Early Head Start (EHS) and Migrant Head Start (MHS) populations. This is still in the planning stages for Virginia. Five Virginia audiologists have volunteered to serve as the training and consult team; five EHS programs have committed to participating. The next step is to identify a program or agency that can serve as the leader to support this project and work toward sustaining the comprehensive screening program once the project ends and expanding physiological screening and follow up into all EHS and MHS programs throughout Virginia. This project includes purchase of screening equipment for the five programs and data reporting/monitoring for one year. The benefits for Virginia EHDI are seen as two-fold. Physiological screening of the Head Start population will identify children whose hearing loss may have developed after the newborn hearing screening as well as help to capture children who may have fallen through the cracks on EHDI follow up.
- VDH collaborated with the Partnership for People with Disabilities at Virginia Commonwealth University on a grant to examine the issue of children with hearing loss who have an additional condition (co morbidity). VDH is in a unique position for collaboration because the Virginia Congenital Anomaly Reporting and Education System (VaCARES) and the EHDI data are in the

same database, and there is access to birth certificate data. The application was submitted this week. The benefits for VDH include evaluation of parent survey data and programming that will allow us to link the EHDI and VaCARES program data using deterministic and probabilistic techniques. This means VDH can efficiently de-duplicate the data in VISITS.

- Ruth Frierson and Pat Dewey attended the national EHDI Conference in Salt Lake City March 26 & 27. Grant funds also supported a parent to attend again this year. During several of the presentations, as well as during the regional meeting, it was clear that Virginia has made good progress toward meeting the national EHDI goals and has tried or implemented many of the things that some states are just beginning to do. Ideas gleaned from this conference include:
  - educating hospitals on importance of reporting accurate information to VDH,
  - initiating hospital site visits,
  - developing scripts for hospital staff to use to communicate screening information to families,
  - importance of ongoing training for audiologists,
  - educating the audiologist as to how the assessment information reported to VDH is used in tracking and follow up,
  - obtaining additional new hearing aids for the loan bank via manufacturer consignment and grants from manufacturers.
- The Joint Committee on Infant Hearing (JCIH) 2007 Position Statement should be out by fall. The revisions to the Assessment Protocols will not be finalized until the updated risk indicators and recommendations for follow up are. EHDI will need to revise the hospital screening protocols, as well as the Medical Protocols, to incorporate the changes.
- Pat Dewey reported that her last day as Program Manager for EHDI would be June 29, 2007. Nancy Ford, supervisor for this position and who has attended meetings in the past, will manage the program until new staff is hired. Nancy Bullock will help Nancy Ford with the GBYS program and the Hearing Aid Loan Bank. The group voted to write a letter to VDH to praise the quality and effectiveness of the work that has been done, to recommend that VDH find someone capable of continuing the work in the same fashion, and to urge that recruitment begin immediately so that the EHDI Program Manager position will not remain vacant for very long.

### **Update from Partnership for People with Disabilities**

Ann Hughes reported on the activities of the Partnership for the training and education contract, supported by EHDI grant funds. Ann reported that she and Debbie Pfeiffer were presenters at the Early Intervention Conference. The presentation was entitled “Risky Business” and addressed the importance of early intervention for children who are deaf or hard of hearing. She also has promoted the GBYS program at several different conferences with displays and/or program presentations.

### **Report on the National EHDI Conference**

Leslie Ellwood reported on his attendance at the conference. He found that Virginia is out in front of the other states with its EHDI program. One issue that is gaining prominence is quality assurance. Several state EHDI organizations are setting up standards for quality of care and collecting information to be able to show proof they are making a difference. Many states still do not have legal requirements for screening. Follow-up issues dominated the discussion and Virginia seems to be ahead of most areas. The evolving science of genetics in conditions that cause deafness and hard of hearing has placed a greater emphasis on including genetic evaluation in the medical evaluations. The trend for an early diagnosis is becoming more and more important for those who want to have a cochlear implant by 12 months. The issues between signed communication and oral communication still exist, but there seems to be less of a battle. The JCIH

recommendations and the new emphasis on the role of the PCP as well as the medical work up were discussed. Leslie Ellwood stated that part of the problem for PCPs is that many have infrequent contact with children who have hearing loss and therefore are not up to date.

### **Update on GBYS**

Dana Yarbrough shared a summary of the project activities for the Virginia GBYS. They received 33 referrals (primarily from EHDI) between January and April 2007; five matches have already been closed. Of the 33, one family declined the match, and one infant died after the first visit. Five were from Richmond, 18 from Northern Virginia, three from Southwest Virginia, one in Danville, and seven from Tidewater. The children ranged from 2 months to 5 years of age. Six of the children had other disabilities. Each family is asked to complete a survey after the guide contact is completed. The Took Kit and the parent resource notebook were shown to the group. The program sent brochures to audiologists and early intervention programs statewide. They would like to send their brochure to pediatricians, but the cost might be prohibitive. The Website has been established and content will be added soon. The “first year pilot” will be over the end of August. VDH and the EHDI grant budget will support the program for one more year, September 2007-August 2008. More family guides are needed and are being recruited. The new “class” of guides will have training in mid-September. It was suggested that the VDH EHDI toll free number be added to tool kit and Web site, since GBYS does not have a toll-free number.

### **Update on the Hearing Work Group**

Beth Tolley reported that the group is now working on a fact sheet for early intervention providers and system managers. This fact sheet will identify a system of resources that is more defined and that can help providers and managers feel more confident about their recommendations. The workgroup also will be developing a curriculum for some on-line training opportunities. The next meeting will be June 8 in Richmond.

### **Report from Follow-Up Coordinator**

Ruth Frierson distributed the draft of a new brochure for parents of children with hearing loss and asked the group for comments. She also distributed draft wording for a new poster. The idea for this poster came from the results of a national survey sent to pediatricians by NCHAM which indicated that a significant number of pediatricians do not know about the EHDI program or about the referral process. The poster would be a useful tool for providing information to both primary medical care providers and parents. The poster will contain information about newborn hearing screening as well as newborn screening and will feature removable information cards. The posters and cards will be produced in English and Spanish and will be distributed to primary medical care providers, obstetricians, local health departments, midwives, and birthing centers.

### **Discussion**

It was moved and seconded that the Advisory Committee write a letter to VDH to (1) urge that recruitment for the EHDI Program Manager position begin immediately in order that the position not remain vacant for too long, (2) communicate high praise for the quality and effectiveness of the work that has been done, and (3) encourage that someone capable of continuing the work in the same fashion be found. The motion passed. Les Ellwood, co chair, will write the letter.

Dr. Ellwood recommended that the next meeting be used to consider candidates for the positions of Chair and Co Chair. The last elections were held several years ago. The Advisory Committee has no bylaws or role description for these positions. The group discussed need to develop a “job description” for these officers.

Dana Yarbrough suggested that the co chair be a parent or an individual who is deaf or hard of hearing. Fredia Helbert recommended that the group develop a list of people, agencies, and groups that should be

represented on the committee. This list can then be given to the Commissioner of Health so that the appointments can be updated. Pat Dewey will develop a list of membership as identified in the law as well as previous groups and organizations with representation. Beth Tolley suggested that a legislator be added to the committee. If appointed, they would get copies of meeting notes with information about the work of the Advisory Committee even if they could not attend the meetings.

The group next discussed ideas on areas of focus for the EHDI Advisory Committee for the coming year. Freida Helbert recommended a continued focus on training for audiologists. Beth Tolley recommended that stable funding for GBYS and the hearing aid loan bank be pursued. Dana Yarbrough suggested keeping track of the co morbidity study, if funded, to learn about the impacts for families and the possible effects on the supports offered by the VDH EHDI Program and GBYS.

### **Next Meeting**

The next meeting will be held on August 10, 2007, at Children's Hospital in Richmond. The final meeting of the year is scheduled for November 9, also at Children's Hospital, Richmond.